

Socio-cultural implications of living with epilepsy: A qualitative study among children and adolescents with epilepsy living in rural Sri Lanka

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Studies on the implications of living with epilepsy in children and adolescents with epilepsy (CAWE) are limited in the Sri Lankan context. This study aimed to describe the life of CAWE in rural Sri Lanka and to identify their quality of life (QoL) issues. Qualitative study comprising 18 in-depth interviews with CAWE, their parents and siblings, and 3 focus group discussions with key informants (primary caregivers, schoolteachers, health-care workers) were conducted in Ampara, Monaragala and Hambantota districts, representing a multi-ethnic rural community in Sri Lanka. Interviews were conducted in Tamil/Sinhala, audio-recorded, transcribed verbatim and translated into English before content analysis. CAWE reported having received decent care and support from parents and siblings. Poor school performance was related to learning difficulties, lack of teachers' support and behavioural problems. Apparently, teasing and name-calling after seizures in public were more common among children than the adolescents. Discrimination and behavioural problems seemed to prevent socialization process of the CAWE. The term 'epilepsy' was found to be socially undesirable implying stigma. Also, we noted a trend in families opting for gentle terms to indicate epilepsy. Unpredictability of seizures, education, employment, marriage prospects, social support and adverse effects of long-term drug treatment were the QoL issues expressed by the parents of the CAWE. Experiences and issues differ for child, adolescent or caregiver making survival with epilepsy a diverse phenomenon for each individual. Community sensitisation is needed to decrease epilepsy unawareness and stigma to improve the QoL of CAWE in this rural community.

Key words: Caregiver, childhood epilepsy, quality of life, seizure, stigma

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